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A National Initiative for Women and Healthcare Providers: CDC's Inside Knowledge: Get the Facts About Gynecologic Cancer Campaign

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Abstract

The Inside Knowledge: Get the Facts About Gynecologic Cancer campaign raises awareness of the five main types of gynecologic cancer: cervical, ovarian, uterine, vaginal, and vulvar. It encourages women to pay attention to their bodies and know what is normal for them so they can recognize the warning signs of gynecologic cancers and seek medical care. This report provides an overview of the development of this national campaign.

Introduction

Each year, about 80,900 women in the United States are diagnosed with and nearly 28,000 women die from gynecologic cancers.¹ A recent report estimates approximately 1 million American women who had been diagnosed with a gynecologic cancer were alive as of January 1, 2007.² The five main types of gynecologic cancer are cervical, ovarian, uterine, vaginal, and vulvar.

In 2007, the most recent year for which data are available, more than 12,000 women in the United States were diagnosed with cervical cancer, and about 4,000 died from it.¹ Cervical cancer is the easiest female cancer to prevent with regular screening tests and follow-up. It is the only gynecologic cancer for which population-based routine screening is recommended. That it is not among the top 10 most common or deadliest cancers is largely because of the widespread use of the Papanicolaou (Pap) test, which screens for precancers (cell changes on the cervix that may become cervical cancer if they are not treated appropriately), and the human papillomavirus (HPV) test, which looks for the HPV, the virus that can cause these cell changes. The HPV test may be used for screening women aged 30 years or at any age for women who have unclear Pap test results.

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Ovarian cancer is the deadliest gynecologic malignancy.¹ Approximately 20,000 women are diagnosed with and about 15,000 women die each year from ovarian cancer.¹ Although an effective screening test for ovarian cancer does not exist, there have been several advances in treatment that have resulted in improved survival from ovarian cancer.³ It is the eighth most common cancer among women in the United States and the fifth leading cause of cancer deaths.¹ Most ovarian cancers are sporadic in nature; however, about 10% of ovarian cancer is linked to genetic syndromes.^{4,5} Women with mutations in the BRCA1 and BRCA2 genes, and those with Lynch syndrome are at greater risk than the general population for ovarian cancer.⁶

Uterine cancer is the most commonly diagnosed gynecologic cancer (fourth most common cancer in women) and is the eighth leading cause of cancer death among American women. Every year, about 41,000 women are diagnosed with and nearly 7,500 die from uterine cancer.¹

Vaginal and vulvar cancers are rare malignancies. In the United States, 1,149 women learned they had vaginal cancer, and 376 died from it, and 4,159 women were diagnosed with vulvar cancer and 865 died from it in 2007.¹ Approximately 40% of vaginal and vulvar cancers have been attributed to HPV.⁷

The Inside Knowledge: Get the Facts About Gynecologic Cancer campaign educates women and healthcare providers about the signs, symptoms, risk factors, and prevention strategies related to cervical, ovarian, uterine, vaginal, and vulvar cancers. Developed and implemented by the Centers for Disease Control and Prevention (CDC), in collaboration with the U.S. Department of Health and Human Services' (HHS) Office on Women's Health, Inside Knowledge supports the Gynecologic Cancer Education and Awareness Act of 2005, or Johanna's Law (www.cdc.gov/cancer/gynecologic/pdf/JohannasLaw.pdf), which was signed into law on January 12, 2007. Johanna's Law authorizes CDC to carry out a national campaign to increase women's and healthcare providers' awareness and knowledge of gynecologic cancers; develop, produce, and maintain a supply of written materials that provide information to the public on gynecologic cancers; distribute materials to the public on request; develop and place public service announcements (PSAs); and call attention to early warning signs and risk factors based on the best available medical information.

Campaign Challenges and Opportunities

A lack of recommended population-based screening for all gynecologic cancers except cervical cancer and the wide range and vague nature of symptoms associated with most gynecologic cancers present distinct challenges for a national awareness campaign. Another significant challenge is that each gynecologic cancer is unique in terms of signs, symptoms, risk factors, and prevention strategies.

For cervical cancer, the main messages of the Inside Knowledge campaign include an action step that most women can take relatively easily: get screened as recommended. For ovarian and other gynecologic cancers, however, key campaign messages center (by necessity) on awareness of risk factors and symptom recognition to promote early detection, timely treatment, and improved health outcomes. The absence of a clear message promoting

screening for ovarian, uterine, vaginal, and vulvar cancers can be frustrating both for women who await the development of effective screening strategies and for the medical and public health communities that lack evidence-based tools to prevent and detect early disease.⁸ All these factors underscore an important need to educate and communicate with women and healthcare providers about gynecologic cancer.

Additional challenges center on what many studies have shown to be common misunderstandings and misconceptions about the Pap test and pelvic examination.^{9–12} Previous studies have reported that women do not know the purpose of a Pap test and believe that it screens for multiple gynecologic cancers, sexually transmitted diseases (STDs), and other conditions.^{8–13} Recent discussions among healthcare providers have also questioned the need and purpose of the pelvic examination.^{14,15}

Knowledge among women about symptoms related to gynecologic cancers also is lacking.^{8,16} Symptom recognition is important for both women and their healthcare providers, particularly in the absence of recommended screening options, especially in the case of ovarian cancer.¹⁷ Without understanding what symptoms are associated with ovarian cancers, for example, women may discount those that are vague and unspecific, and they may go unchecked for some time until symptoms become so persistent or alarming that a woman seeks medical attention.^{18,19} Likewise, educating healthcare providers to recognize symptoms that may be potential signs of ovarian cancer may lead to earlier detection at a more treatable stage.^{20,21} Patients with certain gynecologic and gastrointestinal symptoms²² may benefit substantially from education and awareness or by more active surveillance and diagnostic workup.

Although these challenges exist, they have not been insurmountable, as some common themes can be extracted and applied. For instance, cervical, vaginal, and vulvar cancers have a common thread in their relation to HPV infection, and ovarian and uterine cancers are similar in their age of onset (mainly occurring in postmenopausal women) as well as their possible genetic connection.⁶ Therefore, targeted information to these populations of women is of great value for multiple gynecologic cancers. Education about the gynecologic organ system and functions overall, as well as recommendation of treatment by gynecologic oncologists who more often adhere to guidelines-based care, are two examples of cross-cutting themes that can be applied to every cancer included in the Inside Knowledge campaign.

Development of Campaign Messages

During the initial planning stages of the campaign, CDC conducted an extensive literature review and environmental scan of existing gynecologic cancer educational materials and messages. CDC also developed a logic model for campaign processes, built on formative evaluation, pretesting, process evaluation, and outcome evaluation explained in the Health Communication Process (National Cancer Institute, 2010) that is endorsed by the HHS. The Social Cognitive Theory²³ was the primary theoretical foundation guiding both development and evaluation activities. However, constructs from a variety of other behavioral and communication theories have since been used as needed.

Concurrently, a few months after Johanna's Law was enacted, CDC convened a panel of gynecologic cancer experts in San Diego, CA, to discuss the state of the science and potential education and awareness messages for gynecologic cancers. The panel comprised gynecologic oncologists, gynecologists, pediatricians, nurses, other medical practitioners, health and behavioral scientists, and representatives of nonprofit and advocacy organizations committed to raising awareness of gynecologic cancers.

The general framework and development of Inside Knowledge messages and materials were based initially on what was learned in the literature review and during the expert panel meeting, where information gaps were identified, and consensus was reached on main messages and strategies to raise awareness about gynecologic cancer. Campaign messages were further refined based on focus group research conducted across the United States by CDC to learn more about women's gynecologic cancer knowledge, attitudes, beliefs, and behaviors. In 2009, CDC conducted 48 focus groups in English and Spanish with a total of 408 women (262 English speakers and 146 Spanish speakers) aged 40–60 years in New York City, Atlanta, Miami, Los Angeles, Houston, Chicago, and Las Vegas. In addition to formative research conducted in the focus groups, the groups also served to test creative approaches and strategies to ensure that campaign materials delivered intended messages in the most effective ways.

The main campaign messages are:

- There are several types of gynecologic cancer.
- When gynecologic cancers are found early, treatment is most effective.
- Pay attention to your body and know what is normal for you. Gynecologic cancers have warning signs.
- If you have vaginal bleeding that is unusual for you because of when it occurs or how heavy it is, see a doctor right away.
- If you notice any other unexplained signs or symptoms that last for 2 weeks or longer, see a doctor.
- Get a Pap test regularly to screen for cervical cancer. (The Pap test does not screen for ovarian, uterine, vaginal, or vulvar cancers. Even if you have a Pap test regularly, see your doctor if you notice any signs or symptoms that are not normal for you.)
- Get the HPV vaccine if you are 11–26 years old.
- If you are diagnosed with a gynecologic cancer, see a gynecologic oncologist, a doctor who is trained to treat cancers of the female reproductive system.

Additional Research to Inform the Campaign

In addition to focus groups with consumers as described, Inside Knowledge also conducted formative research with healthcare providers in 2011, using a combination of in-person and telephone focus groups. There were 24 in-person groups, with 6 groups each in Las Vegas, Philadelphia, Atlanta, and Chicago, as well as 6 telephone groups comprising participants

from rural, suburban, and urban areas around the country. Of the 30 groups held (in person and via telephone), 10 included gynecologists, 10 were with primary care physicians, and the remaining 10 were with nurse practitioners. Data analysis from these groups is ongoing, with results informing future campaign development.

Campaign messages and strategies are further informed by Porter Novelli's HealthStyles and DocStyles surveys, from which CDC commissioned questions in 2008 and 2009 to gather baseline information on women's and healthcare providers' knowledge, attitudes, and practices related to gynecologic cancer. HealthStyles is a cross-sectional annual survey of adults aged 18 years that examines beliefs and behaviors about individual health. HealthStyles respondents are asked a variety of demographic questions, including information on age, race, education, and marital status. In addition, CDC commissioned specific questions about gynecologic cancer, including familiarity with and use of screening tests, care seeking for potential symptoms of gynecologic cancer, and concern about getting gynecologic cancer. A series of analyses have been performed with the data collected. Results from the 2008 HealthStyles survey indicate that almost all (about 97%) of the 2,991 women respondents had heard of the Pap test; however, this proportion was lower in women aged 18–34 years and among those who had lower levels of education and income.¹³ Over 80% of the respondents knew the Pap test was used to screen for cervical cancer; however, substantial percentages of women (35%–45%) erroneously thought the Pap test was also used to screen for other gynecologic cancers, such as ovarian and uterine cancer, and for STDs.¹³ Misunderstandings about the purpose of the Pap test were highly prevalent even among women with relevant health experiences, such as those with a history of abnormal Pap test results or a previous cervical cancer diagnosis. Only 17.9% of women respondents correctly identified the Pap test as being a screen for cervical cancer exclusively.¹³ These results indicate widespread misconceptions about the purpose of Pap testing. Another study resulting from the HealthStyles data analysis investigated the knowledge and behaviors of women about the cancer antigen-125 (CA-125) blood test and ovarian cancer. This study showed that about 25% of women reported having heard of the CA-125, with about 10% of women reporting having previously received a CA-125 blood test.²⁴ Characteristics of women who had not heard of or had the CA-125 blood test were similar to those who had, with the exception that those who had heard of it/had it were more often older and perimenopausal or postmenopausal.²⁴ Concern for getting ovarian cancer did not differ significantly among women who heard of/had the CA-125 test compared to those who had not heard of or had it.²⁴ A third analysis from the same survey data examined self-reported intent to seek care for symptoms associated with ovarian cancer. The results showed that gynecologic symptoms (such as post-menopausal bleeding) prompted more intention to seek care than those that would be considered less gynecologic in nature but are, in fact, associated with ovarian cancer (e.g., feeling full after eating a small amount).¹⁶ For most symptoms, postmenopausal women and those concerned about getting ovarian cancer more often responded that they intended to seek care than did younger women and those without such concern.¹⁶ All these studies and data analyses—several of which are continuing—will further help Inside Knowledge campaign planners develop messages and educate women about gynecologic cancer symptoms, including those that are nongynecologic in nature.

DocStyles is an annual survey of physicians who practice in the United States and treat at least 10 patients a week and have been in practice for at least 3 years. One thousand primary care physicians (510 family/general practitioners and 490 internists) and 250 obstetrician/gynecologists responded to our DocStyles questions on HPV vaccination, CA-125, transvaginal ultrasound, and pelvic examination knowledge and beliefs. Analyses from the DocStyles survey indicated that almost 50% of primary care physicians responded that CA-125 alone or CA-125 and transvaginal ultrasound were effective ovarian cancer screens in the asymptomatic, average-risk population,²⁴ a belief that is inconsistent with screening guidelines for ovarian cancer. Obstetrician/gynecologists more often had guidelines-consistent responses, with a little over half (56%) responding that neither CA-125 nor transvaginal ultrasound was an effective screen in the asymptomatic, average-risk population, compared to internists and general or family practitioners. The large percentage of physicians whose responses were inconsistent with current screening recommendations underscores the need for more education about both the current lack of a screening test for ovarian cancer and the potential harms of the CA-125 blood test.

Analyses of data from the 2008 and 2009 surveys are ongoing. In 2009, the Inside Knowledge campaign commissioned similar questions in the HealthStyles and DocStyles surveys, and questions about primary care physician referral patterns to gynecologic oncologists for ovarian cancer care also were asked. These questions probe referrals to and treatment by gynecologic oncologists, as evidence has shown that such referrals, particularly for women with ovarian cancer, result in better survival rates.²⁵ Analyses of these questions can potentially reveal barriers to receipt of appropriate care, and suggest further avenues for targeted education through the campaign.

Patient and Healthcare Provider Materials Development

Inside Knowledge educational materials are developed in consultation with CDC scientists and external gynecologic cancer experts to ensure scientific and medical accuracy. All materials undergo multiple rounds of rigorous review for technical content and consumer appropriateness. The campaign has developed a robust suite of patient education resources, several of which are available in English and Spanish (Fig. 1).

Materials created to date include fact sheets on each of the five main gynecologic cancers, a comprehensive gynecologic cancer brochure, print and broadcast PSAs, posters, out-of-home advertising (such as airport and other transit and shopping mall dioramas), and a gynecologic cancer symptoms diary (Fig. 2). All patient education materials are available for preview or download from the campaign's website, www.cdc.gov/cancer/knowledge. The campaign's website itself is revised and updated periodically, with new features and resources added as they become available. For example, in March 2011, a new feature, Survivor Stories, was added, along with new design elements and photos for the campaign's homepage. The campaign also employs and incorporates novel communication tools, as resources allow, to widely disseminate campaign materials. New technologies and social media channels used to date include Facebook, Twitter, podcasts, CDC Radio, CDC TV, electronic greeting cards, and CDC's YouTube Streaming Health Channel.

The patient education materials created by Inside Knowledge are designed to also be useful to healthcare providers in their communication with patients about gynecologic cancers. To that end, CDC has displayed campaign resources at a variety of healthcare provider professional meetings and presented papers and posters at professional gatherings whenever possible. Development of additional provider materials will be determined by analysis of recently completed provider formative research.

Future materials for healthcare providers likely will emphasize increasing awareness and knowledge of gynecologic cancer etiology, appropriate screening and diagnostic tests (e.g., the role of the Pap test in cervical cancer screening), genomics and cancer risk, symptom recognition, effective communication with patients about gynecologic cancers, and the importance of timely referral to gynecologic oncologists for patients diagnosed with gynecologic cancers. By developing and making such resources available, CDC hopes to increase healthcare provider knowledge of gynecologic cancer issues, which may translate to improved care for women.

Public Service Announcements Development and Dissemination

Inside Knowledge PSAs were developed after focus group research with women around the country to evaluate message salience as well as creative appeal and clarity. In September 2010, Inside Knowledge released its first PSAs: four TV PSAs, four radio PSAs, and three print PSAs, available in English and Spanish. Several of these include women's first-person accounts of recognizing symptoms, seeking a diagnosis, receiving treatment, and being hopeful for a healthy future. The spots urge women to know what is normal for them and inform women that:

Warning signs are not the same for everyone. Know what's normal for you. And if you think something's wrong, see your doctor. Ask about gynecologic cancer. Get the facts. Get the Inside Knowledge.

After launching the campaign's first PSAs in 2010, CDC developed additional TV and print PSAs, as well as other out-of-home advertising, and began releasing them in May 2011. The latest spots feature writer/performer Jenny Allen, a survivor of both uterine and ovarian cancers who wrote and performed a one-woman stage show called, "I Got Sick Then I Got Better." In Inside Knowledge PSAs, she speaks about the importance of recognizing symptoms and encourages women who notice anything unusual to: Be brave, go to the doctor, ask questions (Fig. 3a).

The Inside Knowledge PSAs have been distributed throughout the United States to more than 1,500 English and Spanish network, cable, and local television outlets; 6,200 radio outlets; and 2,000 magazines and newspapers. Out-of-home placements (as of June 2011) include airport dioramas, posters and similar displays in shopping malls, and bus/bus shelter displays. Currently, the campaign relies on donated placements in all media.

PSA Tracking and Process Evaluation

The campaign uses several methods of tracking: monitoring website hits, publication orders, public inquiries, social media and search engine mentions, and PSA use. TV PSA use is monitored electronically, with PSAs specially encoded to confirm when and where they are broadcast. Radio PSA use is similarly tracked through a combination of electronic monitoring and bounce-back cards from stations. Print ad use is tracked using a national media monitoring and clipping service.

Perhaps the most impressive data to date centers on television and radio PSA tracking. Process evaluation shows that as of June 2011, Inside Knowledge broadcast PSAs have generated more than 465,850,445 audience impressions (the number of times they have been seen or heard), worth about \$24 million in donated placements. Affiliate stations of all the major television networks have aired the spots in 131 markets, including 9 of the top 10 and 21 of the top 25 media markets. The TV spots are broadcast at all times of day, with the majority (70%) airing outside the overnight hours of 1 am through 5 am, and 52% airing between 9 am and 10 pm. Meanwhile, the campaign's radio PSAs have aired in more than 125 media markets, including all of the top 10, and at least 20 of the top 25 media markets.

Inside Knowledge TV PSAs also have been shown on Public Health Television, a network installed in reception areas of federally certified rural health clinics, federally qualified health centers, and select critical access hospitals. The network's aim is to reach patients at the point-of-care with targeted, culturally tailored, and linguistically appropriate health education, wellness, and lifestyle programming to improve health outcomes and ultimately reduce healthcare spending. In May 2011, four Inside Knowledge PSAs were aired on this network a total of 43,525 times.

The Inside Knowledge website was launched in August 2009. As of June 2011, it had generated more than 22,000 hits, or visits. Meanwhile, interest in campaign materials is very high. For example, as of July 2011, over 521,000 English and nearly 161,000 Spanish gynecologic cancer fact sheets were ordered from the website. An unknown quantity of materials has been downloaded/printed from the website.

Engaging Stakeholders

Many national and local groups have an interest in the Inside Knowledge campaign, with involvement of several dating to passage of the legislation that created this initiative. Campaign partners include Sheryl Silver, who was instrumental in the creation of Johanna's Law, the legislation authorizing development of the campaign and sister of Johanna Silver Gordon (for whom Johanna's Law was named), the Society of Gynecologic Oncologists, the Foundation for Women's Cancer (FWC, formerly the Gynecologic Cancer Foundation), the Allied Support Group of the FWC; the Ovarian Cancer National Alliance; the National Cervical Cancer Coalition; Fran Drescher's Cancer Schmancer, and many other groups.

CDC works to keep these and all interested parties informed about campaign activities, new resources, and plans. Key partners are important avenues of dissemination for a national campaign, such as Inside Knowledge, and can be critical to its success. To that end, as much

as funding allows, CDC provides free campaign materials to national and local governmental and nongovernmental partners, including those that are part of the CDC's National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and National Comprehensive Cancer Control Program (NCCCP). By taking advantage of the existing infrastructure within CDC-funded state, tribal, and territorial programs (such as the NBCCEDP and NCCCP), the Inside Knowledge campaign can disseminate campaign materials in a cost-effective and efficient manner.

The campaign works with key partners to ensure widespread dissemination of existing campaign materials. To maximize resources and efficiency, Inside Knowledge campaign leaders continue to critically examine, develop, and disseminate materials through collaborative efforts with CDC's Office of Women's Health, HHS's Office on Women's Health, medical professional societies, healthcare providers, and other partners. In all these endeavors, CDC continues to evaluate messaging and materials to ensure they are grounded in the latest scientific findings about gynecologic cancer risk, screening, symptoms, and treatment.

Future Directions

As funding allows, CDC will increase support for activities that will help to inform future implementation of the Inside Knowledge campaign. Evaluation plans include conducting additional process and formative research to assess the campaign's implementation, reach, and public health impact. As awareness and educational resources are disseminated, CDC intends to conduct research to evaluate the effects of the campaign overall and on women's and healthcare providers' knowledge, attitudes, and behaviors related to gynecologic cancers.

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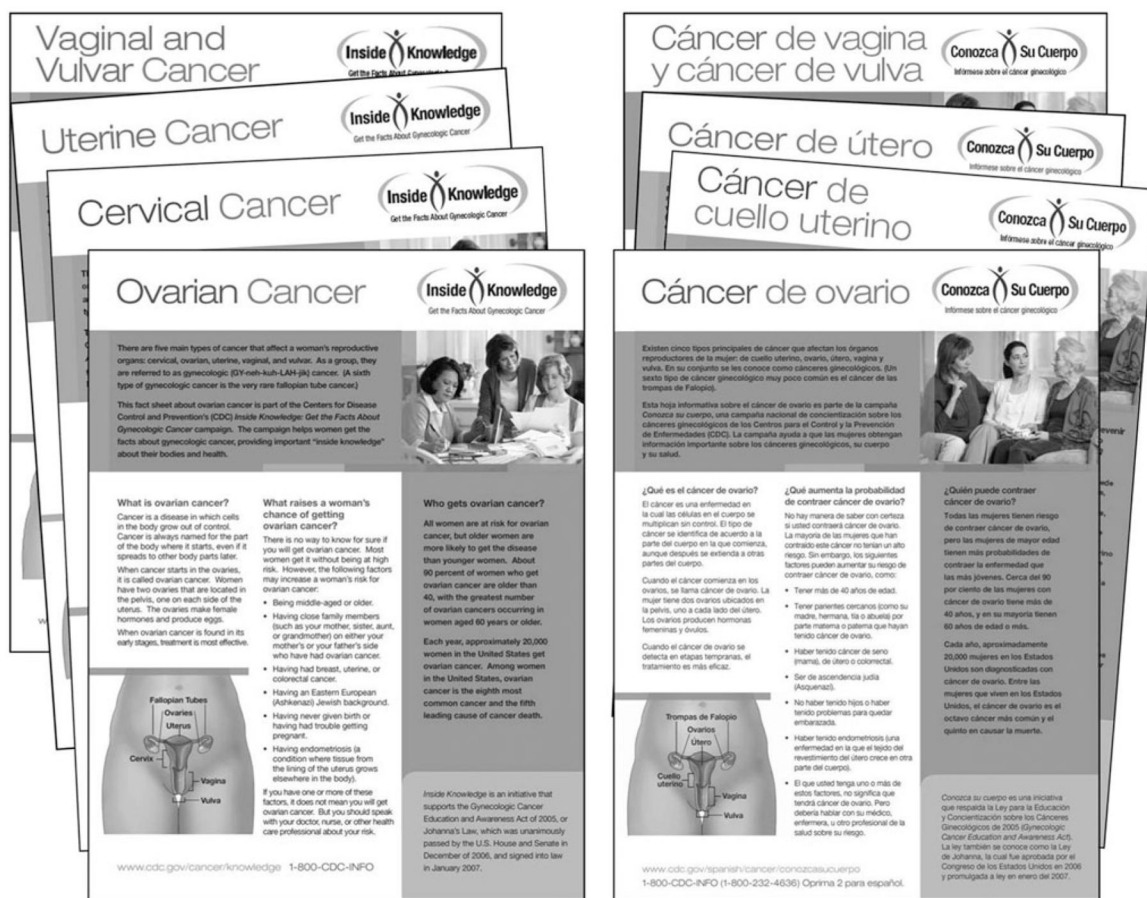


FIG. 1.

Inside Knowledge fact sheets in English and Spanish. All patient education materials can be viewed, printed, and downloaded from the campaign's website, www.cdc.gov/cancer/knowledge. The campaign's website itself is revised and updated periodically, with new features and resources added as they become available.

Gynecologic Cancer Symptoms Diary

Gynecologic cancer symptoms may be difficult to recognize. Fill in the circles in the diary below for each day that you have a symptom. And see a doctor if you have bleeding that's not normal for you or if you have any of the other symptoms for two weeks or longer. It may be nothing to worry about, but find out for sure.



Symptoms	Cervical Cancer	Ovarian Cancer	Uterine Cancer	Vaginal Cancer	Vulvar Cancer	Week One	Week Two
Abnormal vaginal discharge	●	●	●	●		S M T W T F S	S M T W T F S
Pelvic pain or pressure		●	●		●	S M T W T F S	S M T W T F S
Abdominal or back pain		●				S M T W T F S	S M T W T F S
Bloating		●				S M T W T F S	S M T W T F S
Changes in bathroom habits		●		●		S M T W T F S	S M T W T F S
Itching or burning of the vulva					●	S M T W T F S	S M T W T F S
Changes in vulva color or skin, such as a rash, sores, or warts					●	S M T W T F S	S M T W T F S
Abnormal vaginal bleeding	●	●	●	●		If you have bleeding that is not normal for you, see a doctor right away.	

FIG. 2.
Inside Knowledge gynecologic cancer symptoms diary.



FIG. 3. Inside Knowledge print public service announcements. (a) Jenny Allen (top), "Be Brave. Ask Questions." (b) Jennie M. (bottom), "Here's What Happened".